HELPING A FAMILY WITH A PERSON IN THE TERMINAL STAGE OF CANCER BASED ON THE EXAMPLE OF THE GOOD SAMARITAN HOSPICE IN LUBLIN

Abstract. The family is the most secure supporting foundation in the situation of a loved one who is suffering and dying. Its activity results from the strength of intra-family bonds and appropriate legal regulations supporting its actions based on the principle of justice and support. Implementing these activities is based on the social capital of activities arising from the principles of the common good, social love and solidarity. An example is the Social Hospice Care Center operating within the Lublin Society of the Friends of the Sick at the Good Samaritan Hospice, which shows the practical applications of the above course of action within family assistance.

Keywords: family; cancer; dying; hospice.

1. NORMS SHAPING THE PERSONALISTIC SOCIAL ORDER

A world full of different people is the right environment for man’s personal development and living. On the one hand, man is dynamic and capable of development, yet on the other hand, we naturally have to live with others. “By his innermost nature, man is a social being, and unless he relates himself to others, he cannot be called a human being.”

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1 More on this subject in the monograph by Miroslaw Kalinowski, Wspólnoty nadziei. Realizacja zasad życia społecznego w ruchu hospicyjnym (Lublin: Wydawnictwo KUL, 2007), 17–64.

with others, he can neither live nor develop his potential.”

Christian social teaching uses two terms to express man’s communal characteristic: society and community. They define every social body, family, and nation, but also include corporations, associations, trade unions, political parties and institutions helping those in need. Therefore, it can be stated that “God did not create man to be alone, but he called him to live in a community of persons.”

St. Thomas places the human being, with her or his dignity and value, at the center of social life. Man is a rational individual, a substance possessing an independent existence. Society, on the other hand, is a cause that only exists in human persons. Therefore, man is the basic subject of social life. A person is the primary thing, and social life is man’s second nature.

Man’s precedence, being above the community, is justified by the statement that social life has no purpose in itself, since its purpose and goal is to serve man and to provide every person with the goods that cannot be obtained without this collectivity. Every person, therefore, finds themselves at the center of social life as a principle, subject and goal of the community.

The personalist nature of society takes central place in the teachings of John Paul II. Beginning with the encyclical *Redemptor hominis* and going on to *Centesimus annus*, the Pope constantly presents the values that should be objective and indelible in the life of society by virtue of the inviolable and fundamental dignity of every human person as a being created in the image and likeness of God. Respect for the human person means respecting the rights that flow from man’s dignity as a creature. These rights are above the community level and should be recognized by the community.

Personal rights are the basis of the moral righteousness of the social order and all its authorities. By underestimating or rejecting to follow legislation, society undermines its own moral righteousness. If a society begins to negate

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7 Katechizm Kościoła Katolickiego, no 1930; Jan Paweł II, Encyklika *Centesimus annus*, no 10, 13, 44.
an individual’s dignity or to subordinate the human person to pragmatism, this begins to destroy the “protective walls” that defend the basic values of the community itself. The relationship of one person to another person is a relationship of two values, and therefore it can be described as partnership. In such a relationship, man perceives another person as someone good and worth. This results from the conviction that each person is a value in themselves who “we define as personal dignity.” This value seen in a neighbor needs to be recognized, and we must adopt an appropriate attitude towards them, which is expressed above all in actions.\(^8\)

The essence of the life of human communities is the common striving for specific values and accepting chosen goals. In a community, there are two basic tendencies, giving and taking.\(^9\)

The tendency to take from others is due to the fact that social life is an indispensable element of human development and becoming a person. There are many goods and values that an individual person cannot achieve independently without the help and participation of other people.\(^10\) Different types of communities show their insufficiency and the necessity to complement each other, which leads people to cooperate in order to create values that are necessary to sustain life and its comprehensive development. The nature of the community and the scope of their socialization is determined by satisfying human needs. This is due to the fact that the human person is the ultimate subject and purpose of social life.

The tendency to give is the result of the fact that man as a social being feels not only the need to "take" but also to engage and devote himself to others. Without accomplishing these needs, a person’s development is impossible because we exist not only for ourselves, but also for other people.\(^11\)

The consequences of taking and giving are creating and exchanging material and spiritual values that constitute the common good.\(^12\) Man is the creator and the goal of values, so he creates them together with others in order to be

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better and further develop.\textsuperscript{13} We see this truth about man’s communal nature in Divine Revelation:\textsuperscript{14} “God, Who has fatherly concern for everyone, has willed that all men should constitute one family and treat one another in a spirit of brotherhood.”\textsuperscript{15} These common values have a personal character, which means that they are oriented towards the human person. This can be expressed as follows: common values cover all the conditions of social life that allow for full human development at a given level of culture. It is in people, the members of a community, that the meaning of common values is exhausted.\textsuperscript{16}

The community’s ties are particularly important in difficult situations, such as moments of tragedy, suffering or failure. Man, by his involvement in helping other people, secures their goodness and values, taking part in other people’s life events by being aware that these are also his own goods. A civic attitude is born here based on the sense of community and awareness of the common good, meaning good for all of us, motivating us to act on others’ behalf.\textsuperscript{17} John Paul II emphasized the significance of this personalistic order in human communities in the statement that “we cannot exist in a society without a sense of community, commitment and unity, thanks to shared values, compassion and responsibility for another person.”\textsuperscript{18}

The rule of subsidiarity is of particular importance when caring for terminally ill people. In the situation of suffering and death, helping activities mostly center on simply accompanying a patient. It is easier for a man to agree with the fact of his upcoming death when he knows that someone will be at his side and stay with him until the very last moment, helping him as best as possible.\textsuperscript{19} “Accompanying” means a good attitude towards the patient, which is actually “being together,” “being with another human being, not just standing next to them,” providing vigilant attention to his or her needs, with cordiality, listening and understanding.\textsuperscript{20}

\begin{itemize}
\item \textsuperscript{13} Piwowarski, ABC katolickiej nauki społecznej, 37.
\item \textsuperscript{14} Borutka, Mazur, Zwołński, Katolicka nauka społeczna, 40.
\item \textsuperscript{15} Sobór Watykański II, Konstytucja duszpasterska o Kościele, no 24.
\item \textsuperscript{16} Piwowarski, ABC katolickiej nauki społecznej, 62.
\item \textsuperscript{17} Skorowski, Być chrześcijaninem i obywatelem dziś, 84–85.
\item \textsuperscript{19} Antoni Bartoszek, Człowiek w obliczu cierpienia i umierania. Moralne aspekty opieki paliatywnej (Katowice: Księgarnia św. Jacka, 2000), 208–209; Zbigniew Wałęszczuk, W trosce o człowieka umierającego. Geneza Hospicjum w Polsce (Wrocław: Lamis, 2004), 47.
\item \textsuperscript{20} Mirosław Kalinowski, Towarzyszenie w cierpieniu. Posługa hospicyjna (Lublin: Polihymnia, 2002), 31; Jerzy Drążkiewicz, “O ruchu hospicyjów w Polsce,” in W stronę człowieka
\end{itemize}
The principle of subsidiarity in Catholic social teaching is defined as the norm that shapes the individual’s obligations in society, including a smaller community’s obligations towards a greater one. This is based on the fact that larger societies provide complementary help to smaller communities, and all larger and smaller communities help every individual human person. It obliges individual people, social groups, civic associations, religious associations, the entire governments of individual countries and international institutions to jointly build the common good of humanity, for the sake of their competences and resources.

The subsidiarity rule is treated as the basic natural-legal norm, important for various aspects of the functioning of human communities as a result of fulfilling three basic functions: the observance of autonomy (functioning as a guarantee and to protect), multidimensional support (an auxiliary function), and shaping social attitudes (a pedagogical function).

On the one hand, the subsidiarity norm protects the autonomy of one’s individual life and the life of the community, and on the other hand, it is linked with intervention and help “from top to bottom.” Supporting a larger human population can be undertaken for two reasons. First of all, this happens when individual people or smaller groups are unable to fulfill the tasks entrusted to them. Second, this applies to activities that can only be undertaken by larger social organizations, because larger systems arise from the fact that neither a single person nor a small group are self-sufficient.

In other cases, there cannot be a situation where someone is denied the fundamental right to pursue their personal goals. On the one hand, stronger societies have a greater duty to know about the problems that affect people in a given environment, and on the other, they are to help the weaker societies by stimulating, supporting, and coordinating their actions with the activ-


ities of other groups in order to achieve the common good.\textsuperscript{24} Thus, an important function of the principle of social justice is to secure the rights of every human individual on the public-legal level in such a way as to grant them privileges that result from man’s natural dignity.\textsuperscript{25} The protective function of social justice is important in the case of terminally ill patients. Physical exhaustion means that dying patients are included among the weakest people, those who cannot defend their personal status by themselves. Therefore, it might happen that patients experience a violation of their dignity and rights as a result of caretakers neglecting the duties imposed on them as a result of objectification or also robbing them of the property they own.\textsuperscript{26}

2. LEGAL CODIFICATIONS

Appropriate legal regulations needed by state authorities are not an act of mercy, but an act of social justice.\textsuperscript{27} The Constitution of the Republic of Poland\textsuperscript{28} lists two important human rights which are of fundamental importance for the type of care of persons who are in their terminal phase of cancer. According to article 38 of the Basic Law, “The Republic of Poland shall ensure the legal protection of the life of every human being.” However, access to institutions dealing with health services is guaranteed by Article 68 § 1 due to the fact that “everyone has the right to have his health protected.” Patients are to receive health benefits regardless of their age, background, economic or social position, and also regardless of the illness or infirmity.

In raising the quality of a patient’s life in their terminal phase of cancer, in 1993, the Committee of Ministers of the European Union created a system of recommendations for palliative care.\textsuperscript{29} The adopted recommendations

\textsuperscript{25} Józef MAJA, Etyka życia gospodarczego (Wrocław: Wydawnictwo Wrocławskiej Księgarni Archidiecezjalnej, 1982), 29–30; BORUTKA, MAZUR, ZWOLIŃSKI, Katolicka nauka społeczna, 50–51.
\textsuperscript{27} M. RADZYNSKI, Sprawiedliwość i miłosierdzie w dysponowaniu dobrami materialnymi (Warszawa, 1959), 113.
\textsuperscript{28} Dz. U. 1997, Nr 78, poz. 483.
state that the governments of member states, including Poland, take into account the following matters:\textsuperscript{30}

1. to undertake programs, legislation and other activities necessary for developing the standards for consistent and comprehensive national legal regulations at palliative care facilities;

2. to promote the development of international cooperation among organizations, research institutions and other active structures of palliative care.

According to the presented instructions, palliative care is an integral part of the health care systems of European Union member states, and therefore its availability, maintenance, financing and detailed development plans should be included in the state strategy in the field of health care.\textsuperscript{31} The dynamic development of the hospice movement also contributed to the fact that in 1990, the World Health Organization published a document confirming this type of care to be a new branch of medicine called palliative care, and it has two main tasks. First, it is to relieve a dying person’s pain, and second, it is to provide direct and indirect help to prepare the patient for death, and if he or she gives their consent, to spiritually prepare them to meet with God.\textsuperscript{32}

According to the directives in the Constitution of the Republic of Poland and European Union recommendations, the range of services provided by Poland’s hospices is regulated by the Act on August 30, 1991 on health care institutions.\textsuperscript{33} This is shown by the fact that article 2 of this Act mentions places dealing with health care services in a stationary hospice, including other places not mentioned by name, such as other places intended for people whose state of health requires providing 24-hour or day-care services.

The scope of health services includes activities aimed at maintaining, saving, restoring and improving a patient’s health, particularly everything related with palliative and hospice care (Article 3 point 10 of the Act). The norms included in the Constitution of the Republic of Poland and their detailed specifications in the form of the act on health care institutions require

\textsuperscript{30} Report of the WHO Expert Committee, 12.
\textsuperscript{31} Ibidem.
\textsuperscript{33} Dz.U. 1991 Nr 91, poz. 408.
that the state ensure the proper functioning of facilities providing palliative and hospice care.

Based on art. 31d of the Act on August 27, 2004 on health care services financed by public funds, the Minister of Health issued the ordinance on August 29, 2009 on the benefits guaranteed in the field of palliative and hospice care. It introduced a new quality of activities at the above-mentioned institutions, and especially social centers operating over the years under the Act on Associations and the Act on Public Benefit and Volunteer Work.

A significant act improving the activities of hospice facilities was the Regulation of the Minister of Health on October 29, 2013 on guaranteed services in the field of palliative and hospice care that entered into force on December 5, 2013.

The “Hospice Charter” was announced at the First Congress of the National Hospice Movement Forum in Gdańsk and states that “the goal of hospice care is to enable the patient to properly go through the terminal period of their illness by symptomatic and conditioning treatments and accompanying the patient and his family along the difficult path of suffering that they undertake together.”

The implementation of the above-mentioned entry is present in the statutes of hospice communities. An example is article 7 of the Statute of the Lublin Society for the Friends of the Sick at the Good Samaritan Hospice, which states that the goal of the Society’s activities is to:

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34 Dz.U. z 2008 r. Nr 164, poz. 1027, z późn. zm.
35 Dz.U. z 2009 r. Nr 139, poz. 1138.
38 Rozporządzenie to uchyliło wcześniejsze akty Ministra Zdrowia: Rozporządzenie MZ z dnia 29 sierpnia 2009 roku, Rozporządzenie MZ z dnia 8 grudnia 2009 r. oraz Rozporządzenie MZ 24 stycznia 2011 r.
—provide people who are seriously and terminally ill from cancer with medical and spiritual care adapted to the special needs of these patients;
—provide help for families of the severely sick people in caring for the sick;
—unite people of good will who are ready to provide the above with social care and help.

3. THE GOOD SAMARITAN HOSPICE IN LUBLIN

The Lublin Society of Friends of the Sick in Hospices was officially registered at the Voivodship Court in Lublin on October 11, 1989, validated on November 1, 1989. The Hospice was renamed the Good Samaritan Hospice in 2000. The Polish Social Committee located on Lipowa street was the headquarters of the Society for several years and conducted homecare for the sick, including organizing courses for volunteers. In August 1993, at the Society’s request, the Lublin City authorities proposed refurbishing the building to make it meet the standards of a stationary hospice.

Its renovation was completed in 1997 by admitting the first patients to a ten-bed stationary ward. The Hospice Care Center was established, which included people working with patients on the basis of an employment contract. In 2005, the decision was made to expand the hospice, requiring arduous documentation work for the purchase of more land, making agreements with the historical monument conservator and securing funds. The budget program of Lublin Voivodeship for the years 2007–2013 included the revitalization of the historic region of the city, and this program co-financed the activities of the Hospice. The hospice’s expansion that started in March 2011 was completed in March 2013, with an additional 10 beds in the stationary care ward, rooms for seven home care teams and a room for the families of the patients, volunteers and administration.

Hospice funding is provided by the National Health Fund and the City Office (their tender offer), which covers about 65% of the budget, and addi-

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40 “Lubelskie Towarzystwo Przyjaciół Chorych rozpoczyna działalność,” Kurier Lubelski (6.12.1989). It was the twelfth in Poland and the first in the Lublin region; The Society operates on the basis of the Act on Associations of April 7, 1989 (consolidated text Journal of Laws 2001 No. 79, item 855 with later amendments) and based on the act on Public Benefit and Volunteer activity on April 242003 (Journal of Laws from 2003 No. 96, item 873).

41 Employment in various kinds of work: 10 doctors, 24 nurses, 8 room cleaners, 2 psychologists, 2 physiotherapists, 1 chaplain, 2 drivers-conservators. In 2016, the number of employees of the medical division increased to 16 doctors and 32 nurses. LTPCH Report for 2016, p. 2.
tional funds (about 35%) are supplemented by the Association (1% tax deductions, material donations, financial collections from parishes, during funerals and other occasions, and volunteer work by the Board). The Society provides free public benefit activities in the area of public works such as: protecting and promoting health, it is called to participate in the terminal care of people who are very sick and to help the families of these patients.\textsuperscript{42}

The goal of the Society is to provide holistic care to cancer patients who are terminally ill, especially providing medical, psychological and spiritual care. Very important in this process in the Hospice are the patient’s closest relatives. Helping the families of sick people in caring for patients is an integral part of the hospice’s complementarity ministry. In a climate of those serving life in its final stage, people of good will gather together, ready to voluntarily provide the above care and assistance.\textsuperscript{43} The Society’s many tasks, in addition to working at a patient’s bedside, include activities related to the propagation of the hospice along with methods of caring for the sick and lonely people. This particularly includes those who are in their final phase of life or do not have proper conditions at home during their illness.

In making people aware of the above social solidarity activity, there are courses, conferences and seminars organized within the Society. An important area in promoting attitudes supporting these dying people is cooperating with social communication centers. Permanent elements of annual cooperation are the world days of hospice care and the world day of the sick, and there are many other activities, such as auctions and concerts for the hospice.\textsuperscript{44}

The Good Samaritan Hospice in Lublin has been cooperating with academic staff at the Medical University of Lublin for many years. Students of the Faculty of Medicine and the Faculty of Health Sciences hold internships, training sessions and discussions in the field of palliative medicine and hospice care at the Lublin Hospice. Several years ago, the group also began to include English-speaking students.\textsuperscript{45} In cooperation with external entities, training sessions and courses in the field of palliative medicine are held for the needs of the Lublin Chamber of Nurses and Midwives.\textsuperscript{46}

\textsuperscript{42} Statut Lubelskiego Towarzystwa Przyjaciół Chorych Hospicjum Dobrego Samarytanina, art. 1–2.
\textsuperscript{43} Ibidem, art. 7.
\textsuperscript{44} LTPCH Report in 2015, p. 3.
\textsuperscript{45} From the medical department—400 students, nursing department—60 students. Report from the LTPCH activities in 2016, p. 3.
\textsuperscript{46} NOVUM Association, Lublin Chamber of Nurses and Midwives training for 110 people. Ibidem.
In order to implement the statutory tasks, the Hospice annually applies for the funding competitions at the National Health Fund (NFZ) in the field of palliative and hospice care. Each contract with NFZ covers 56% of the expenses of the hospice facility. In the 2016 fiscal year, the average cost per day/person in a stationary hospice was PLN 339, and NFZ reimbursed PLN 210. In accord with the standards of medical facilities, the Hospice also cooperates with the City Council’s Health Department and other health care institutions in healing and nursing patients.

4. FORMS OF ASSISTANCE TO FAMILIES AT THE GOOD SAMARITAN HOSPICE IN LUBLIN

Actions are undertaken to help families in five areas: the hospice house is a stationary hospice with twenty-two beds, the stationary hospice is a care team going to homes, a palliative medical clinic, a hospital pharmacy department and support for orphan family members. The first four areas of assistance activities helping families are included in the medical services covered by the National Health Fund. The last of these services is offered thanks to the good will of the hospice community and the existing people potential.

The stationary hospice provides care to about 400 patients annually (in 2016, there were 393 patients). The number of man-days in stationary care was 8,310, and the average time of stay in the hospice was 21 days. Over 90% of the hospice’s charges are Lublin residents, and the remaining people come from the following districts: Lublin county (Leczna, Swidnik, Belzyce) and others (e.g. Nieniec). The cost per person per day was PLN 339, and funding from the National Health Fund (NFZ) per person/day was PLN 210.

The home hospice includes about 300 patients annually (in 2016, 289 patients received hospice support), 19,188 man-days were carried out that year, the average care period was 65 man/days, the cost of one man/day was 41 zlotys, and NFZ’s funding was PLN 36. Service cars are used in the field work: 6 passenger cars and 1 ambulance. The ambulance transports patients to diagnostic medical tests, driving them to the Hospice and back to their family homes.

The palliative medicinal clinic provides about 70 consultations annually (in 2016, 49 consultations were given to 21 patients), the cost of counseling came out to PLN 111, and the NFZ refunded the hospice PLN 37. Homecare and counseling services are provided up to 30 km away from the institution’s headquarters.
Hospice lends rehabilitation and nursing equipment on a loan basis. In 2016, 102 patients benefited from this equipment. Among others, beds, variable-pressure mattresses, anti-bedsore mattresses, wheelchairs, walkers, portable toilets, and oxygen tanks were rented out.

The Pharmacy Department directly serves the stationary residential facility and people who are in home care, cooperating with many commercial entities. Purchasing medicine, wound dressing materials, disinfecting agents, etc. in 2016 cost PLN 315,208.

The Good Samaritan Hospice cares for the people closest to those who are dying, both at our stationary and home care. During psychological and emotional difficulties, support is provided by the members of the hospice team who have psychological training. The constant availability of psychologists gives both the dying and their loved ones a sense of security. The range of help and therapy provided depends on the individual needs of people. Information and training activities are offered in the form of lectures for family members interested in the above issues. Individual meetings are available every day at the offices of psychologists employed at the hospice.

An important area of support for orphan families includes the spiritual dimension undertaken by volunteers and the hospice chaplain. Spiritual care is a complementary part of the activities of the hospice team. It is widely accepted that the spiritual condition of a sick person has a significant impact on the effectiveness of medical activities and the effectiveness of psychological support.

Spiritual support is connected with many issues that have a significant impact on its effectiveness. Previous research shows that this should primarily include a global assessment of spiritual care, preferred criteria for defining it, the subject providing spiritual assistance and the expectations associated with it.\(^{49}\)

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\(^{47}\) Urtica (medicine, enteral and parenteral nutrition), Lubfarm (medicine, infusion fluids), Tuttomed (medical equipment and materials for dressings), Sanofi (Clexane, No-spa amp); Zakrzewski Dental (needles for ports), Camedica (medicine and materials for dressings).


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associated with it, the type of spiritual care and the role and importance of religious practices.

The largest group of respondents believe that in spiritual care, the most important thing is awareness of the 24-hour availability of the hospice team, the presence of closest relatives, the presence of a chaplain, and solidarity among the greater hospice family. The availability of the members of the hospice team in terms of spiritual care, as well as in the case of medical and psychosocial assistance, ranks first among the patients’ expectations.

Awareness that they are supported by a group of people ready to help at any time is essential for terminally ill patients, and constant access to people is in itself a form of spiritual care. Even without taking on a physical form, spiritual care fulfills the task of supporting and accompanying a dying patient. A chaplain is among the team members who is important in this ministry due to his predisposition in terms of spiritual support. In the opinion of patients, this is reflected in the statements of people involved in hospice work, and the whole team provides spiritual care for the dying patient, while the hospice chaplain’s work addresses a patient, his family and the hospice team.

In spite of the helplessness of the environment in stopping a disease, with a good measure of success, we can help to alleviate its progressive stages. In the opinion of family members, it is very important for the hospice team to keep in mind man’s relation to the spiritual sphere. The family members of a hospice patient are characterized by a high degree of unity in compassionate suffering, expressed in their opinions on spiritual care that is solidary with the suffering people and the greater hospice family. This directly affects interpersonal relationships, our overcoming barriers between healthy and sick people and strengthening social bonds.

In summary, it should be stated that all the activities of the hospice team that focus on the dying person constitute helping activities for their closest family. The Good Samaritan Hospice in Lublin fulfills its mandate by wholeheartedly responding to the existing demands of the institution’s patients and their families.

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